

# Contributing to Improved Health through New Knowledge: Primary Care Teams and the Unanswered Questions

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'To myself I seem to have been . . . playing on the sea shore, and diverting myself in now and then finding a smoother pebble or a prettier shell than ordinary, while the great ocean of truth lay all undiscovered before me.' (Sir Isaac Newton, 1642–1727)

What are the causes of diabetes? Why is the incidence rising? How does environment interact with genetic predisposition to determine the natural history of diabetes? What determines risk of complications within subpopulations? How can diabetes be prevented, or managed cost-effectively? What contribution can primary care teams make to unanswered questions such as these?

At first sight, we may feel not much; if Sir Isaac Newton was abashed in the face of the undiscovered ocean how much more should we be, preoccupied enough with our daily fishing at the surface?

In this article I argue that not only are there many smooth pebbles and pretty shells for the sharp-eyed practitioner to pick up, from unusual case presentations to new technologies, but that the very enterprise of the application of evidence-based medicine to practice<sup>1</sup> depends on the research contribution of the primary care team, who because of, not despite, their daily clinical work, have a unique contribution to make and who care for the vast majority of illness presenting to the National Health Service, including diabetes. It is the realism of clinical experience with individuals grappling with illness and disease amidst the pressing priorities of life that doctors, nurses and other primary care workers bring to a consideration of the research agenda. This realism is needed most importantly in the framing of research questions from a primary care perspective, but also in the sensitive recruitment of patients to collaborate in research, in the inclusion of measures of appropriate patient-centred outcomes, and in the design of feasible studies, manageable in the primary care setting.

## Incongruity and Innovation: Smooth Pebbles and Pretty Shells

Picking these out can be difficult if one is short-sighted, in a hurry, or always has one's eye on the horizon. They are more likely to jump into the hands of the curious—arguably a vanishing breed in hard-pressed primary care, where 'tolerating uncertainty' can so easily transform itself into its suppression, at least to the level of nagging doubt, rather than celebration as an opportunity to learn, to invent, or to discover. Daily contact with individual patients can encourage innovation, both conceptually and technically.

## Case Studies

I would like to see more case studies coming from primary care practitioners, illustrating the unexpected, the incongruous in our practice. An example from my own experience was a home visit to a child with Type 1 diabetes, apparently in a hypoglycaemic coma but with a high blood glucose on home blood glucose testing; worrying about this led to some domestic science and a report of 'sticky fingers' factitious hyperglycaemia.<sup>2</sup> But while diabetes can be understood as applied biochemistry and physiology, management will be most effective if diabetes is also understood in terms of patients' experiences of illness, since patients' attitudes and behaviour in self-care make such a major contribution to disease outcomes. Case histories describing the different ways in which patients perceive and respond to the diagnosis of diabetes and its treatment may give us further clues as to the most effective management strategies to follow for different individuals.<sup>3</sup>

## New Technology

Within the series of papers in this supplement, several innovations shine out—new technologies that may overcome observed obstacles to effective care. One is the 'borrowing' of the monofilament from leprosy to diabetes, in order systematically to improve recognition of the at-risk foot—a development championed by Gadsby.<sup>4</sup> Another is the Stockholm bus, used to deliver primary-

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care-based fundal photography to 77 % of the study population, with known diabetes, in Stockholm County in the 1990s—twice as many as were reached by the usual referral-based organisation of care—and associated with a reduction in new blindness in diabetes of more than a third.<sup>5</sup>

In our own development of new approaches to diabetes care from diagnosis, simply following patients through primary care annual review consultations, from practice nurse to general practitioner, identified duplications of health promotion advice that provided the potential for replacement with more opportunity for patient participation.<sup>6</sup>

## Asking the Right Questions

Careful observation and description of the chains of events in individual patient care and service delivery can identify weak or redundant loops and lead to initiatives to develop more effective care. In the words of Douglas Black in his recent reflection on the limitations of evidence,<sup>7</sup> 'What I seek to emphasise is the importance of the prior intellectual analysis of the problem, be it clinical or organisational, in such a way as to define the type of evidence that is going to be relevant. An unstructured search for evidence may only lead to confusion.' This is equally true of the processes by which we spot incongruity and innovate, and by which we move on to produce evidence through enumeration and evaluation.

## Enumeration and Evaluation

### *Questions for Descriptive Epidemiology*

We still have a big task on our hands in terms of simple descriptive epidemiology of our populations with diabetes, around 50 % of whom are not seen in secondary care. We still need to establish the incidence and prevalence of diabetes and its associated complications in different at-risk groups. Do you care for ethnic minorities, or have responsibility for nursing homes? Has anyone adequately counted their care?<sup>8</sup>

### *Questions for Longitudinal Studies*

We need to move beyond the cross-sectional survey to longitudinal studies—and while I do not underestimate the enormous infrastructural effort required to do this, one of general practice's great strengths is (still) the registration and care of patients over time. The energy to exploit such registration is clearly there as described in this supplement in contributions, for example, from Lanarkshire<sup>9</sup> and Stockholm County.<sup>5</sup>

Again, imaginative analysis of the questions to be answered must be established first. Longitudinal data collection for research purposes should surely be hypothesis driven, collected cyclically rather than continuously,

from representative samples rather than whole populations, and adequately funded so as to get the data out and analyzed as well as in. Given such discipline and resource, a primary care diabetes network with good academic partnership could respond well to the MRC's call to study 'the emergent illness experience [of diabetes] following early diagnosis' which 'merits descriptive and comparative research to establish the most effective approaches to management'.<sup>10</sup>

### *Questions for Aetiological Studies*

Primary care teams are used to taking the long view; with sufficient academic partnership and inter-practice collaboration, there is the potential to set up frameworks within which aetiological questions can be answered, over a generation or more. This depends on the belief that knowledge of natural history does take time to unfold, and that the shortcuts of case control and retrospective cohorts available are no substitute for definitive prospective work. For example, early studies of concordance rates for Type 2 diabetes among monozygotic twins described very high rates but it is now accepted that, depending as they did on recruitment from diabetic clinics, they suffered from selection bias towards concordance.<sup>11</sup> Why could primary care teams not report twins from their whole list—not an arduous job and salient enough to remember—and monitor, track and observe both birth weight, and growth and development, the tracking of glucose tolerance, and the eventual incidence of diabetes, in a less biased way? Why cannot primary care teams think imaginatively about the importance of subgroups in throwing light on aetiology; among low birth weight babies, what are the determinants of the metabolic syndrome for example; or within families with mothers, fathers or siblings with diabetes, how does cardiovascular risk and diabetes distribute and track over time? That cohort studies can be cost-effectively conducted in general practice, is shown by the landmark RCGP oral contraception study.<sup>12,13</sup>

### *Questions for Experimental Studies*

To be feasible and generalizable, new approaches to management must reflect strategies that primary care practitioners can use. To take an example from elsewhere; the appropriate use of antibiotics in sore throat in general practice has not been established by placebo-controlled, double-blind trials of antibiotic prescription. A considerable advance has been made in an open pragmatic trial of 3 strategies; where randomization was to antibiotics prescribed, not prescribed, or offered with delay.<sup>14</sup> The results showed surprising adherence to the strategies, no difference in duration of symptoms between them, but more frequent subsequent attendance with sore throats among those prescribed antibiotics. To carry out this trial required practitioners with a high level of curiosity

and uncertainty, who were willing to randomize their approaches to care: in diabetes there is plenty of uncertainty and curiosity to organize in this way. For example, there is increasing interest in the contribution of the interaction between practitioner and patient to patient adherence, well-being and health status. In particular, patients' perception of having found common ground in the consultation is associated with better outcomes.<sup>15</sup> Further studies are needed to confirm or test these observations. Could primary care teams not compare different strategies for achieving common ground within the consultation on patients' perceptions, well-being, adherence to treatment and metabolic control?

## Questions of Service Provision

The appropriate configuration of services is affected by prevalence of the disorder, its severity, and the skills and technology available to modify outcomes. While specialists in secondary care settings think naturally about models of disease-specific outreach care for general practice (the diabetes specialist nurse and the mini clinic, and absolute standards of care), generalists in primary care think more naturally about generic models of care, of diabetes as an extension of cardiovascular risk reduction, or chronic disease care, of the value of the practice nurse or GP who can integrate the management of diabetes with that of asthma, arthritis and depression, and of goals related to individual patient preference. We still know too little about the generalizability or cost-effectiveness of these different models of care, each of which offers plausible advantages and disadvantages. Imaginative collaborative studies between primary and secondary care colleagues are needed here. Such studies will require us to study our own attitudes and behaviour as well as that of our patients; not least because systematic differences between professions and settings are likely to confuse our patients and build obstacles to best care.<sup>16</sup>

There is a host of questions to answer in relation to simple aspects of service delivery. What strategies will best allow maintenance of patients in the right sector of care, and reduce inappropriate specialist or primary care drift? How frequently should patients be called for follow-up? Prompted care in general practice may be associated with greater frequency of contact than in outpatients<sup>17</sup>—is this necessary, or cost-effective? On the flip side, what strategies might reduce defaulting from diabetic clinics—Griffin's review of the evidence suggests that this behaviour is associated with poor outcomes and gives some excellent leads for imaginative health services research.<sup>18</sup> Health services research also goes beyond best treatment to consider cost-effective strategies for early detection, screening and prevention—an area of particular relevance for primary care research.<sup>10</sup>

## New Paradigms for Research

With the recent White and Green papers on primary care<sup>19</sup> and the public health,<sup>20</sup> a new attitude favourable to patient participation in research,<sup>21</sup> community action and action research frameworks is with us; the MRC Topic Review stresses that 'the process of development of an intervention to be assessed by a randomized trial is of equal importance to the trial methodology itself, and needs to be funded accordingly'.<sup>10</sup> With the responsibilities for health improvement, clinical excellence, and clinical governance that are envisioned for primary care groups come the responsibility of developing appropriate research and development strategies and capacity in primary care.<sup>22</sup> In this supplement Pierce describes how we can access the skills we need to frame and answer questions relevant to our practice.<sup>23</sup> In the company of the many colleagues we need to help us in this endeavour—from anthropologist to epidemiologist—I wish us all happy beachcombing.

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